Alzheimer's Disease Biennial Report 2012

Texas Council on
Alzheimer's Disease
and Related Disorders

Message from the Chair

Alzheimer's disease is an age-related, progressive, and irreversible brain disease which currently affects an estimated 5.4 million Americans. Alzheimer's disease manifests itself in problems with memory, thinking, and behavior severe enough to interfere with everyday life. Alzheimer's disease gets worse over time. As cognitive and functional abilities decline, individuals are rendered totally dependent on others for all of their care. Currently, there is no effective prevention, treatment, or cure for Alzheimer's disease.

The Texas Council on Alzheimer's Disease and Related Disorders (Council) is composed of 17 members including 12 voting members who are appointed by the Governor, Lieutenant Governor, and Speaker of the House. Five non-voting members represent the Health and Human Services Commission (HHSC), Department of State Health Services (DSHS), and Department of Aging and Disability Services (DADS).

On behalf of the Council, I am pleased to present the 2012 Biennial Report of activities and recommendations in accordance with Texas Health and Safety Code, Chapter 101, 70th Texas Legislature. This report details the highlights of Fiscal Years 2011 and 2012.

The Council's work could not be accomplished without the direct support of DSHS staff. Council members join me in the continued effort to address the burden of this chronic and devastating disease on our Texas citizens and those who care for them.

Debbie Hanna, Chair

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Executive Summary

In Texas, an estimated 340,000 individuals are now living with Alzheimer's disease (AD) and that number is projected to increase to 470,000 by 2025. Nationally, Texas ranks third in the number of AD cases and second in the number of AD deaths. Moreover, Texas ranks second nationally in the amount of uncompensated care provided by caregivers. By year end (2012), the direct and indirect costs of AD and other dementias are projected to exceed $200 billion, nationally.[1]

Alzheimer's exacts an enormous toll on individuals, families, the healthcare system, and American businesses. It is a serious problem affecting many aspects of our society. Until AD can be prevented, treated or cured, the impact of this disease will only continue to intensify.

The Council's dedicated and experienced members combine their skills in **discharging their legislative mandate** by:

- Recommending needed action for the benefit of persons with Alzheimer's disease and related disorders and their caregivers.
- Encouraging public and private family support networking systems for primary family caregivers.
- Disseminating information on services and related activities for persons with Alzheimer's disease and related disorders to the medical and health care community, the academic community, primary family caregivers, advocacy associations, and the public.
- Actively participating in and making recommendations to interagency workgroups that promote successful aging for Texans.
- Encouraging research to benefit victims of Alzheimer's disease and related disorders.
- Facilitating coordination of state agency services and activities relating to victims of Alzheimer's disease and related disorders.

During the past two years, the Council made **significant progress** in its work, including:

- Assisting the Texas Legislature with their work on House Resolution 1978, Regular Session, a joint interim study on the overall economic and systemic impact of Alzheimer's disease through 2017.
- Directing state appropriated funds to the Texas Alzheimer's Research and Care Consortium, as mandated, for Alzheimer's disease research in Texas.
- Advancing the implementation of the *2010-2015 Texas State Plan on Alzheimer's Disease.*
- Developing the first Texas guidelines for the early detection, diagnosis, and pharmacological treatment of AD.
- Coordinating the activities of the Texas Alzheimer's Disease Partnership, a volunteer group of more than 150 individuals who actively advance the state plan and promote awareness of Alzheimer's disease in Texas.

The Council has identified the following **priority issues** which require immediate attention during the next biennium:

1. Sustain and support ongoing research efforts to identify modifiable risk factors to help delay the onset, prevent, and/or cure AD.
2. Increase collaborative AD research among Texas researchers.
3. Advance Texas' infrastructure and capacity to be commensurate with the state's increasing burden of AD through creating both public and private innovative partnerships and relationships.
4. Optimize the system of care and supports for AD caregivers.
5. Continue to expedite the implementation of the *2010-2015 Texas State Plan on Alzheimer's Disease.*

It is the Council's expressed goal to support the Texas Legislature in its efforts to establish Texas as a global leader in Alzheimer's disease research and care.

Alzheimer's Disease – An Urgent National Health and Research Priority

Alzheimer's disease (AD) is a progressive and irreversible brain disorder characterized by a steady decline in cognitive, behavioral, and physical abilities severe enough to interfere with daily life. Hallmark symptoms of AD are memory loss, disorientation, and diminished thinking ability followed by a downward spiral that includes problems with verbal expression, analytical ability, frustration, irritability, and agitation. As the disease progresses, physical manifestations include loss of strength and balance, and the inability to perform simple tasks and physical activities. As more of the brain becomes affected, areas that control basic life functions like swallowing and breathing become irreversibly damaged, eventually leading to death. New criteria and guidelines for diagnosing AD were proposed and published in 2011, recommending that AD be considered a disease that begins well before the development of symptoms.[1]

The course and progression rate of Alzheimer's Disease varies from person to person, ranging from an average of five to eight years to more than 20 years from the onset of symptoms.

AD affects an estimated 5.4 million Americans today - 340,000 of those individuals are Texans. It is the sixth leading cause of death in the U.S. and has an economic burden that exceeds $200 billion annually. Texas ranks third in the number of AD cases and second in the number of AD deaths. A new person develops AD every 68 seconds, and current projections indicate that this rate will increase to one new case every 33 seconds by 2050. In 2011, there were an estimated 15 million unpaid caregivers in the U.S., most of who were family members. **In Texas, 1.3 million unpaid caregivers provided care to the 340,000 individuals with Alzheimer's in 2011. This equates to 1.5 billion hours of unpaid care at a cost of $17.6 billion per year.[1]**

A diagnosis of AD presents many challenges. Although Alzheimer's is not a normal part of aging, it is considered an age-related disorder. **Alzheimer's affects up to 13 percent of people 65 and older and increases to 45 percent at age 85 and older.[1]** These rates

take on increasing significance when we consider that the U.S. population older than 65 is expected to double by 2030 and the number of individuals with AD is estimated to reach 7.7 million.[1] **By 2050, without effective prevention, treatment or cure, the number of individuals with AD aged 65 and older is projected to triple to between 11 and 16 million.[1]** With the first wave of baby boomers having reached age 65 in 2011, AD and other age-related diseases will rank among the leading causes of morbidity and mortality. At least 15 million baby-boomers will develop AD or a related disorder in their lifetime, imposing great significant economic and human ramifications for an already burdened society. [1]

Total payments for health care, long-term care and hospice care for individuals with AD and other dementias are projected to increase from $200 billion in 2012 to $1.1 trillion in 2050 (in 2012 dollars).[1] This figure may be conservative when one considers the results of the Koppel Report, that looked specifically at AD related expenditures by American businesses.[2] The report focused on two areas: (1) the cost to businesses for family caregivers, and (2) the business share of health and long-term care expenditures for people with AD. Caregiving costs included absenteeism, productivity losses, and replacement costs of workers who care for loved ones with AD, and were estimated to be $36.5 billion per year. Additionally, the business share of healthcare for people with AD, plus taxes toward federal funding of AD research were calculated at $24.6 billion each year. The combined total equals $61.1 billion annually. The study also compared current figures with a similar study published in 1998, when business expenditures were calculated at $33 billion for the year. [2, 3] Costs almost doubled in this timeframe. Further, these cost projections were based on the current estimate of Americans who had AD and are projected to rise exponentially with an accelerated growth in the aging population.

WHAT ECONOMIC VALUE DO WE ASSIGN TO THE EFFORTS OF THE MILLIONS OF INFORMAL CAREGIVERS WHO PROVIDE LONG-TERM CARE AT NO CHARGE TO THEIR FAMILY MEMBERS?

In 2008, the total per person payments from all sources for healthcare and long-term care for Medicare beneficiaries with AD and other dementias were **three times greater than payments for other Medicare beneficiaries in the same age group** ($43,847 per person for those with Alzheimer's and other dementias compared with $13,879 per person for those without Alzheimer's and other dementias). Medicare and Medicaid cover approximately 70 percent of the cost of care.[1]

Costs to American businesses are staggering, but represent just a portion of total healthcare and long-term care expenditures for AD. They do not, for example, reflect the billions of dollars spent by state and federal governments on Medicare and Medicaid, nor the out-of-pocket expenses incurred by family caregivers. Much of the care provided to individuals with AD is considered custodial care and insurance policies typically do not cover it.

Families are the caregiving heart and soul for the millions of individuals whose lives have been so dramatically altered by AD. Of the more than five million Americans with AD, 80 percent live at home and receive most of their care from family members. Caregivers of people with Alzheimer's and other dementias provide care for a longer time, on average, than caregivers of older adults with other conditions.[1] Each caregiving experience presents its own special circumstances and challenges. As the person with AD requires increasing levels of supervision and personal care, this can result in caregivers experiencing greater levels of stress and negative effects on health, employment, income and financial security. **Although caregivers report positive feelings about caregiving, including family togetherness and satisfaction from helping others, they also report high levels of stress over the course of providing care. Caregivers frequently become isolated, over-burdened, and depressed.** One study noted that caregivers of individuals with dementia are twice as likely to have significant adverse health issues versus those who care for someone not suffering with dementia.[4] The same study noted caregivers' frequent need for assistance in both providing direct care and in managing the needs of the person with AD. Caregivers have also been found to have more health problems than others of the same age because of the physical and emotional demands of caregiving.[1] A close relationship between the

caregiver and the person with AD - a relationship involving shared emotions, experiences and memories - may place caregivers at even greater risk for psychological and physical illnesses.[1] The human toll on AD patients and the informal network of family and friends in charge of their care is inestimable.

Progress Through Research and Advocacy

MOST EXPERTS AGREE THAT AD, LIKE OTHER COMMON CHRONIC DISEASES, DEVELOPS AS A RESULT OF MULTIPLE FACTORS RATHER THAN ONE SINGLE CAUSE.[7] THESE FACTORS INCLUDE A VARIETY OF BRAIN CHANGES THAT CAN BEGIN 20 YEARS PRIOR TO THE SYMPTOMS OF AD APPEARING.

While AD has no clear cause and its pathology is not fully understood, its degenerative effects on the brain are clear. In recent years, much has been learned about the causes of AD, resulting in a more clearly defined recognizable clinical pattern. These findings have helped to clarify differences between normal age related memory changes, Mild Cognitive Impairment (MCI), AD, and other dementias. While MCI involves memory impairments with preservation of daily functional ability, AD causes fundamental changes in multiple realms of cognition and behavior. MCI may in some cases represent a transitional state between normal aging and the earliest symptoms of Alzheimer's.[7]

The time between the initial brain changes of AD and the symptoms of advanced AD are considered by scientists to represent the "continuum" of Alzheimer's. At the beginning of the continuum, the individual is able to function normally despite these brain changes. Further along the continuum, the brain can no longer compensate for the increased damage caused by brain changes, and the individual begins to show subtle declines in cognitive function. In some cases, physicians identify this point in the continuum as MCI. Towards the end of the continuum, neuronal damage and death is so great that the individual shows obvious cognitive decline, such as memory changes or confusion as to time or place.[1]

Research continues to expand our understanding of the causes of, treatments for, and prevention of Alzheimer's disease.[6] Scientists have identified genetic and biological changes that occur with AD, allowing them to pinpoint possible targets for treatment. **Advances in pharmacologic treatment may stabilize and delay progression of AD symptoms.** This delay in progression helps contain costs associated with medical and long-term care, eases caregiver burden, and allows the individual with AD the opportunity to participate more fully in life and postpone inevitable dependency.

The aging population is dramatically increasing the incidence of AD. This will have significant economic and human ramifications on our society. While other causes of death have been declining in recent years, deaths due to AD have been rising. **Between 2000 and 2008, deaths due to heart disease, stroke, and prostate cancer declined by 13 percent, 20 percent, and 8 percent, respectively, whereas deaths attributable to AD increased by 66 percent.[1]**

Public Health Challenge and Research Priority

AD is a major public health and research challenge because of its detrimental effects on the health and well-being of the nation's population. These effects will only be amplified over the next two decades in the wake of our burgeoning aging population. Unless AD can be effectively prevented, treated or cured, the number of Americans with AD will increase significantly. Though progress has been made in diagnosing AD and in symptomatic and disease-modifying treatments, there remains no cure for this disease.[6]

Because there is no cure for AD, the importance of early detection becomes even more critical - the earlier the diagnosis is made, the more likely the individual may respond to treatment. Additionally, many conditions with dementia-like symptoms are reversible. Other benefits to early detection include decreased medical costs, improved safety

EARLY IDENTIFICATION AND AGGRESSIVE TREATMENT OF AD AND OTHER DEMENTIAS OFFER THE GREATEST OPPORTUNITY FOR A REDUCTION IN THE RATE OF DISEASE PROGRESSION AND IMPROVED QUALITY OF LIFE FOR THE INDIVIDUAL LIVING WITH AD.

for the individual with AD, opportunities for caregiver education and access to caregiver supports, and advanced planning of personal and legal issues while the individual with AD can still participate.

Despite its importance, significant barriers remain to early detection. As cognitive and functional decline worsens, it renders individuals with AD less likely to seek care on their own and reduces their effectiveness in reporting their disease effects. Many individuals with AD do not recognize that they are impaired. This can range from mild denial of impairment to frank unawareness of the disease. In earlier stages of AD, individuals often mask their symptoms by attributing them to old age and by ordering their environment to provide cues to remember people and events. Often, it is not until the individual's thinking and behavioral difficulties worsen when family members and friends become alerted to a problem and seek medical help. For those individuals with AD who live alone, the identification of a problem may be even **further delayed** because of their cognitive impairment, which makes it less likely that the individual can recognize dangerous situations or problems in performing tasks that are critical for daily living.[1] **A missed or delayed diagnosis of AD can lead to unnecessary burdens on the individual and their caregivers.**

HAVING GREATER CAPACITY THROUGHOUT TEXAS TO REACH A POSITION OF LEADERSHIP IN THE GLOBAL FIGHT AGAINST AD REQUIRES US TO DEVELOP AN INFRASTRUCTURE EQUAL TO THE CHALLENGE AND TO DEVELOP CAPABILITIES COMMENSURATE WITH THE STATE'S INCREASING BURDEN IMPOSED BY ALZHEIMER'S DISEASE.

Ongoing research efforts to find causes and identify risk factors to delay onset and prevent and cure AD are imperative. As methodologies are refined, scientists and clinicians will be able to investigate and understand the earliest pathological and clinical signs of AD – perhaps 10 to 20 years before a clinical diagnosis is made. Drug development to block the progression of symptoms and eventually prevent AD is critical to decreasing disability and death, containing health care costs, and protecting individuals and families.

Increased support for individuals with AD and their caregivers is crucial. Stakeholders must continue to advocate for community and home-based care and community supports for caregivers, because these programs afford caregivers **the assistance they need to help care for their loved ones at home.** Advocacy for these services and identifying new sources of services has become even more important with discontinuation of the Community Alzheimer's Resources and Education Program in Texas.

Expediting statewide, coordinated action to address AD in Texas remains critical as the prevalence of the disease continues to climb, exacting huge human and economic burdens on Texas citizens and resources. The *2010-2015 Texas State Plan on Alzheimer's Disease* makes a compelling case for increased and coordinated statewide action and provides a clear roadmap for addressing the significant issues AD imposes on Texas. Continued implementation of the plan will greatly benefit Texans by guiding the state in its efforts to reduce the burden of AD on our citizens and those who care for them.

Texas Council on Alzheimer's Disease and Related Disorders

Background and Overview

Recognizing the growing problem of age-related neurodegenerative diseases, the 70th Texas Legislature passed House Bill 1066 in 1987 (Chapter 101, Texas Health and Safety Code), creating the Texas Council on Alzheimer's Disease and Related Disorders. The Council was established to serve as the State's advocate for persons with AD and their caregivers.

Specifically, the Council serves to increase awareness of AD and its impact on Texans, participate as a strategic partner and coordinating body for statewide education and research activities related to AD, and to support policies and programs that benefit people with AD and their caregivers.

Council Activities - Awareness and Education

Websites

DSHS maintains a website containing information on AD, warning signs, diagnosis, treatment, legal and financial issues, options for care, and information on licensed nursing and assisted living facilities certified for AD care. Council meeting agendas and minutes, and helpful toll-free phone numbers and internet links are also available on this site, at www.dshs.state.tx.us/alzheimers/default.shtm.

The Texas Alzheimer's Research and Care Consortium (TARCC) maintains a website with information and updates on research activities, information on TARCC institutions and committees, publications, research recruitment opportunities, contact information, and AD statistics and resources. This website can be accessed at http://www.txalzresearch.org/

Toll-Free Helpline

Since its inception in 1987, the Council has worked to develop a growing awareness of the tremendous impact AD and related disorders have on individuals, families and society. DSHS maintains a toll-free information helpline (1-800-242-3399) to provide information, support, and referrals to local community services.

Advocacy

The Council, in its continued efforts to advocate on behalf of individuals with AD and their families, provides guidance to community and state agencies on program and policy development.

Statewide Strategic Planning

Recognizing that AD is a growing public health concern, the Council and DSHS Alzheimer's Disease Program began formal work in 2009 on the development of the **first, comprehensive state plan to address the current and future burden of AD on our state.** Knowing that this work would require partners and stakeholders from state, local and community level organizations; academic and research institutions; for-profit and non-profit sectors; businesses; the healthcare sector; and family members of individuals afflicted with Alzheimer's disease, the Texas Alzheimer's Disease Partnership was formed. **This partnership is a volunteer group** comprised of individuals with diverse backgrounds and rich and varied experiences, which provided the synergy and expertise to create a strategic blueprint for formulating and implementing a comprehensive and coordinated statewide plan for Texas. While there is still work to be done, great progress has been made over the past two years.

Partnership Development

The Council, in its efforts to coordinate, collaborate and support Alzheimer's related services and programs throughout the state, is engaged with developing partnerships with service organizations, health organizations, commissions, and

aging-related agencies. Council members and DSHS staff serve on boards, advisory and planning committees, **guiding the direction and promotion of programs designed to assist individuals with AD and their caregivers.** The Texas Caregiver Support Program, Texas Respite Coalition, Silver Alert Program, and Aging Texas Well Advisory Committee are examples of ongoing collaborations and support.

Caregiver Support Program

Meeting the challenges of caregiving requires many resources. DADS and its 28 Area Agencies on Aging (AAAs) form a statewide network to provide comprehensive information and services for caregivers. The Council assists the Caregiver Support Program by serving as a resource, providing referrals, and marketing the program through the DSHS website.

Coordinated Alzheimer's Disease Research

The Texas Legislature made history in 2005 by approving the first state-level appropriation for AD research in the nation. This initial $2 million investment provided start-up funding for the TARCC, a collaborative research effort without precedence in Texas. The Council, through legislation, was directed to establish a consortium of AD centers among four of Texas' leading medical institutions: Texas Tech University Health Sciences Center (Texas Tech), University of North Texas Health Science Center (UNTHSC), the University of Texas Southwestern Medical Center at Dallas (UT Southwestern), and Baylor College of Medicine (BCM). In 2007, the Texas Legislature nearly doubled the state's initial investment in TARCC. This made it possible to recruit 500 Texans with AD and 300 healthy control subjects into the Texas Harris Alzheimer's Study to participate in cutting edge biomedical research. Participants regularly undergo a battery of tests and provide annual blood and DNA samples at TARCC member sites. The resulting uniformly collected clinical, neurocognitive and laboratory data is combined in the centralized Texas Alzheimer's Data Bank, based at UT Southwestern. **TARCC has established the first Texas bio-bank of stored blood, tissue and DNA to**

support current and future AD research studies. Researchers across the state are able to utilize these unique Texas resources to answer specific questions about AD, both now and in the future, as new information leads to new ideas.

In 2008, the Council expanded the reach of AD research into South Texas by adding the University of Texas Health Science Center – San Antonio to TARCC. This move, coupled with the 2009 state appropriation of $6.85 million, enabled TARCC to begin including a large number of Hispanic individuals into the Texas Harris Alzheimer's Study. One third of Texans are Hispanic, and according to the Texas State Data Center, Texas will become a majority Hispanic state between 2025 and 2035. **The inclusion of underrepresented Hispanics significantly strengthens AD research efforts in Texas, and uniquely positions Texas to assume a national leadership role in this largely untapped area of AD research.**

TARCC's Current Research Objectives

Capitalizing on progress to date, TARCC researchers are aggressively pursuing important cutting-edge research objectives aimed at 1) improving efficiency of early diagnosis, 2) clarifying disease mechanisms, and 3) enabling more effective disease prevention. In its current biennium (September 2011– August 2013), TARCC is working on:

- **Development of a serum protein-based tool for predictive AD diagnosis.** A blood-based test will allow for earlier and more accurate detection of AD. Because of the time between the development of AD and the onset of symptoms, early diagnosis can greatly benefit development of new treatment therapies and perhaps lead to improved methods to delay or prevent AD onset.

- **Discovery of new genes associated with the development of AD.** The discovery of new genes associated with Alzheimer's risk is likely to lead to the development of new drugs and therapies that will improve the quality of life of patients with Alzheimer's and ultimately prevent this devastating disease.

- **Discovery of genetic variants within inflammatory genes associated with AD development.** Identification of inflammatory genes associated with AD will allow for discovering treatments aimed at reducing chronic inflammation levels. Because a number of FDA-approved anti-

inflammatory drugs are currently on the market, rapid and effective progress may be made in this arena if inflammatory genes are identified as important AD risk factors.

- **Evaluation of the roles of altered cholesterol and insulin metabolism in development of AD.** If cholesterol and altered insulin metabolism are shown to be important Alzheimer's risk factors, therapies aimed at moderating these factors may be indicated.

- **Resolution of the relationship between cardiovascular risk factors, inflammation and AD.** Identification of inflammation as the key trigger resulting in cardiovascular risk factors increasing the risk for Alzheimer's may enable physicians to prescribe more effective heart disease medications to help prevent or delay AD onset.

- **Evaluation of the roles of key cardiovascular risk factors in AD development and progression.** If elevated blood levels of homocysteine or Lp-PLA_2 (two key markers of cardiovascular disease risk) are shown to be important Alzheimer's risk factors, therapies aimed at moderating these factors may be indicated.

- **Evaluation of depression and depressive symptoms at various stages of cognitive decline.** Research results would allow clinicians to more accurately predict risk for depression among their patients with AD who are at various stages of cognitive decline.

TARCC's research activities are reviewed by an external advisory committee of national leaders in Alzheimer's research to assure that TARCC adheres to the highest quality research standards and pursues a direction with the greatest potential to break new ground in AD research.

TARCC Achievements

Each TARCC site recruits individuals who are diagnosed with AD, Mild Cognitive Impairment (MCI), or healthy aging controls. Blood samples of TARCC participants undergo advanced analyses of proteins, metabolic, and genetic data. Demographic information, clinical histories, and neuropsychological functioning are also assessed. **To date, TARCC has enrolled 2,096 participants into the Texas Harris Alzheimer's Study, including 952 patients with a primary diagnosis of AD, 833 cognitively normal individuals and 311 subjects with MCI.** These numbers include 519 Hispanic individuals. Given this impressive success and current patient accrual rates, **TARCC is ahead of schedule to meet the target of 1,700 active participants by August 2013.**

All blood samples are sent to UT-Southwestern for processing, DNA extraction, handling, and storage in TARCC's dedicated bio-banking facility. This facility is also responsible for preparing and shipping samples for all laboratory analyses (see section below). Tracking of all tissue samples through all steps is facilitated by the software program Freezerworks to ensure this valuable resource is maintained for current research interests as well as for future projects that require stored DNA, whole blood, plasma, and serum on a cohort of well characterized individuals.

TARCC researchers have been highly productive, not only in regard to producing cutting-edge data, but by reporting important scientific discoveries. More than two dozen important manuscripts have been published in the past three years that describe numerous advancements in our understanding of AD. Topics of these reports include:

- **Novel tools to help doctors more accurately diagnose AD.** TARCC researchers have developed a novel blood test for Alzheimer's that uses state-of-the-art micro-array analysis of serum proteins to predict disease risk. A National Institutes of Health grant is under review that proposes to validate the ability of this blood test to diagnose AD in an independent group of samples and assess whether this test can predict disease progression as well as discriminate between non-AD forms of dementia. This discovery was published in the September 2010 Issue of the Archives of Neurology.[5]

- **Methods to better track disease progression.** TARCC researchers have documented a simpler, more accurate method to measure smaller incremental changes in dementia progression through use of an alternative score for measurement of cognitive ability. Owing to the increased range of values, the new score offers several advantages over the previous version, including increased utility in tracking changes within and between stages of dementia severity.

- **Associations between inflammation and mental performance**. TARCC researchers have discovered that a pattern of inflammatory proteins exist in AD and is a powerful mediator of cognitive impairment and rate of disease progression. This pattern offers preliminary evidence of one possible biological pathway for cognitive and functional decline among a subgroup of individuals and has direct therapeutic implications.

An Early Return on the State's Investment

Texas-based AD research continues to benefit the state in many ways, such as:

- **Advances in detection**. Using a multidisciplinary/translational approach, that includes blood biomarkers, genetic material, imaging and neurocognitive data, as well as psychological, neuropsychological, behavioral and general medical information, Texas researchers are working to develop new methods for early detection of AD.

- **Ability to predict risk.** Recruitment and follow-up of normal elders along with AD patients will enable scientists to better understand factors leading to increased disease risk. TARCC researchers have begun this process by looking at information on biomarkers, lipid metabolism, genetics and clinical testing as they relate to the disease. However, many more factors remain to be examined. Early identification of AD risk will make it possible to create therapies to prevent or delay onset of disease.

- **Better tracking of AD progression.** By leveraging Texas' medical and university infrastructure, Texas-based scientists can identify individual differences among patients that influence the rate of disease progression. Data gathered from these studies will help identify new therapies to slow progression and improve quality of life for patients with AD.

- **The best in personalized medicine.** Texas scientists can use advances created by Texas-based research initiatives to develop new treatments that address a patient's individual AD "profile," as defined by specific genetic, blood biomarkers and general medical, behavioral, psychiatric, and other risk factors.

- **Advances in basic science.** While great progress has been made, researchers are still searching for definitive answers to questions about the basic mechanisms of AD. Advancing greater understanding of these mechanisms through basic research can benefit Texas by expanding the pipeline of scientific discovery and identifying additional targets for treatment.

Council Recommendations, FY 2013-2014

As the state's appointed advocate for persons with AD and their caregivers, the Council respectfully submits the following recommendations:

1. Coordinated Alzheimer's Disease Research

The Council requests **continued recognition and support of coordinated statewide research** demonstrated by the Texas Legislature when it passed House Bill 1504, 76th Legislature, 1999, (Chapter 154 of the Texas Education Code) establishing the Texas Consortium of Alzheimer's Disease Centers. **The Consortium, later named TARCC by the Council, provides Texas with the infrastructure for sharing vital AD research information and clinical outcomes.** It provides a framework for expanding and expediting the search for answers about the causes, methods to delay onset and stop disease progression, and eventual prevention and cure of AD.

2. Increased Collaborative Research among Texas AD Researchers

Increasing **collaboration in AD research** across public, private, state and federal sectors that cut across disciplines **is needed to quicken discovery**. Exploring lifestyle modifications, such as diet and exercise alone, is insufficient, as pharmacological and behavioral interventions must be integrated in order to develop therapies aimed at AD prevention. This type of multi-disciplinary research is typically not funded by national health and science foundations, and offers significant opportunities to study disease progression and advance therapeutic strategies. Outcome-oriented research projects backed by appropriate funding mechanisms and **active collaboration among Texas researchers are critical** to clarify and streamline pathways for increasing preventive and risk-reducing therapies.

3. Continued Support for Quality Long-Term Care

The Council supports **maintaining or increasing** current levels of nursing facility eligibility for people with cognitive impairments, specifically AD and other related dementias.

The Council requests maintaining or increasing Resource Utilization Groups (RUGS), based on level of need, to accommodate higher levels of reimbursement for facilities that care for persons with cognitive impairments.

4. Expanded Community-Based Programs and Services

The Council recommends **expansion and optimization** of home and community-based programs and services for individuals with AD and their caregivers. The Council recommends the expanded availability of affordable respite care, training for caregivers, and other resources to maintain the integrity of the family caregiving system. Elimination of the Community Alzheimer's Resources and Education program left a significant gap in these services for families who need them most. Because **family caregivers provide the vast majority of care**, expanding these resources will afford caregivers much needed services to assist them in caring for their loved ones with AD.

5. Coordinated Statewide Plan Implementation

The Council recommends **ongoing and expedited implementation** of the activities outlined in the *2010-2015 Texas State Plan on Alzheimer's Disease*. This plan provides the strategic blueprint, that when fully implemented, will enable Texas to better address the complex issues associated with the increasing prevalence of this disease. **Texas requires greater capacity to address the huge economic and human toll AD places on our valuable resources and citizens.** To confront the fastest growing disease in the county, limited and competing resources must be carefully directed at comprehensive and coordinated statewide strategic planning. The state of Texas must remain proactive in the face of the burgeoning epidemic of AD.

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Appendices

Appendix A

Texas Council on Alzheimer's Disease and Related Disorders 2012 Member Roster

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Appendix C

Telephone and Web Resources

ALZHEIMER'S ASSOCIATION **1-800-272-3900**

Information on Alzheimer's disease, care, support, and research.

www.alz.org

- Comprehensive Alzheimer's disease information for family caregivers, healthcare providers, researchers and the media on risk factors, diagnosis and treatment options; day-to-day care; legal and financial planning; insurance coverage; current research; and Association news releases.

www.alz.org/findchapter.asp

- Links to local chapters for available programs and services.

ALZHEIMER'S DISEASE AND MEMORY DISORDERS CENTER **1-713-798-4734**
BAYLOR COLLEGE OF MEDICINE

Clinical and basic science research; education; and diagnosis and treatment of patients with Alzheimer's disease and related disorders.

www.bcm.edu/neurology/alzheimers/

- Drug trials; research projects; brain donation program; patient appointments and evaluation; and Alzheimer's disease information.

ALZHEIMER'S DISEASE CENTER **1-214-645-8800**
THE UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER

Scientific research into the causes of Alzheimer's disease; and diagnostic evaluation of adult memory problems.

www.utsouthwestern.edu/utsw/cda/dept23589/files/46161.html

- Clinical research studies; patient evaluation process; newsletters; educational events; and caregiver resources.

ALZHEIMER'S DISEASE EDUCATION AND REFERRAL (ADEAR) CENTER **1-800-438-4380**

Provides current and comprehensive Alzheimer's disease information and resources from the National Institute on Aging.

www.nia.nih.gov/alzheimers

- Research updates; directory of National Institute on Aging Alzheimer's Disease Centers; clinical trials database; recommended reading list for caregivers; and press releases.

MEDICAID HOTLINE **1-800-252-8263**

Toll-free number for general information and counseling on Medicaid.

www.hhsc.state.tx.us/medicaid/

- General information on the Texas Medicaid program.

CENTERS FOR MEDICARE AND MEDICAID SERVICES **1-800-633-4227**

National toll-free number for general information and counseling on Medicare.

http://www.cms.gov/

- Official U.S. government site for information on Medicare/Medicaid eligibility, enrollment, and premiums.
- Search tools for state-specific information on health plan choices; nursing home comparisons; prescription drug programs; participating physicians; and plan coverage.

OFFICE OF THE ATTORNEY GENERAL CONSUMER PROTECTION DIVISION **1-800-621-0508**

Register complaints against businesses; report senior fraud.

www.oag.state.tx.us/consumer/index.shtml

- Senior Texans' information on consumer protection; rights of the elderly; choosing a nursing home; advance planning; health and safety; and Senior Alerts.

TEXAS ALZHEIMER'S RESEARCH & CARE CONSORTIUM **1-512-925-3320**
Information about state-funded collaborative Alzheimer's disease research at participating Texas medical schools and health science centers.

www.txalzresearch.org

- Latest research publications by TARCC researchers, press releases, a history of state involvement in Alzheimer's disease research, and a resource list for Alzheimer's disease patients and their caretakers.

TEXAS DEPARTMENT OF AGING & DISABILTY SERVICES **1-512-438-3011**
Information on long-term aging and disability services.

www.dads.state.tx.us/

- Administers long-term services and supports for people who are aging and who have cognitive and physical disabilities. Also licenses and regulates providers of these services, and administers the state's guardianship program.

AREA AGENCIES ON AGING **1-800-252-9240**
Services to help older Texans, their family members and caregivers obtain information and assistance for locating and accessing community services.

www.dads.state.tx.us/contact/aaa.cfm

- Information on services for persons 60 years of age and older. Services include healthcare benefits counseling; case management; nutrition services; transportation; in-home help; senior centers; and the Retired Senior Volunteer Program (RSVP).

LONG TERM CARE OMBUDSMAN PROGRAM **1-800-252-2412**
Advocates for quality of life and care for residents in nursing homes and assisted living facilities.

www.dads.state.tx.us/news_info/ombudsman/index.html

- Identifies, investigates and resolves complaints made by, or on behalf of, residents and provides services to help in protecting the health, safety, welfare and rights of long term care consumers. Provides information and assistance in choosing the most appropriate living residence.

- **CONSUMER RIGHTS AND SERVICES** **1-800-458-9858**
Takes complaints about the treatment of people who receive services in long-term care facilities or in their homes.

www.dads.state.tx.us/services/crs/index.html

- Information for consumers and providers on different types of long-term care facilities; quality ratings and comparisons; how to file a complaint about a facility; and provider training opportunities.

DADS CAREGIVER SUPPORT PROGRAM **1-800-252-9240**

- In-home and community-based services for individuals who are elderly or disabled.

www.dads.state.tx.us/services/caregiver.html

LEGAL HOTLINE FOR OLDER TEXANS **1-800-622-2520**

- Legal assistance including counseling, representation, and document preparation.

TEXAS DEPARTMENT OF INSURANCE **1-800-252-3439**

Information, counseling, and filing complaints against private insurance providers.

www.tdi.state.tx.us/consumer/hicap/hicaphme.html

- Health information, counseling and advocacy; insurance fraud; and publications for seniors.

TEXAS DEPARTMENT OF STATE HEALTH SERVICES **1-800-252-8154**
DIVISION FOR MENTAL HEALTH/SUBSTANCE ABUSE SERVICES

Consumer rights for mental health protection.

www.dshs.state.tx.us/mhsa-rights/

- Community programs, services and standards for persons with mental health and substance abuse issues.

TEXAS DEPARTMENT OF PROTECTIVE AND **1-800-252-5400**
REGULATORY SERVICES

Takes and investigates reports of abuse, neglect, or exploitation of children, the elderly, and/or people with disabilities.

www.dfps.state.tx.us/

- Services for children, adults, and people with disabilities, including investigation of reports of abuse, neglect, and exploitation at home or in facilities licensed by state agencies; and arranging for protective services. Protective services may include referral to other programs; respite care; guardianship; emergency assistance with food, shelter, and medical care; transportation; and counseling.

TEXAS TECH UNIVERSITY HEALTH SCIENCES CENTER **1-817-735-2506**

Scientific research on Alzheimer's disease and aging; patient evaluation and care through their many clinics; and geriatric and long-term care education through the Garrison Institute on Aging.

www.ttuhsc.edu/centers/aging/vision.aspx

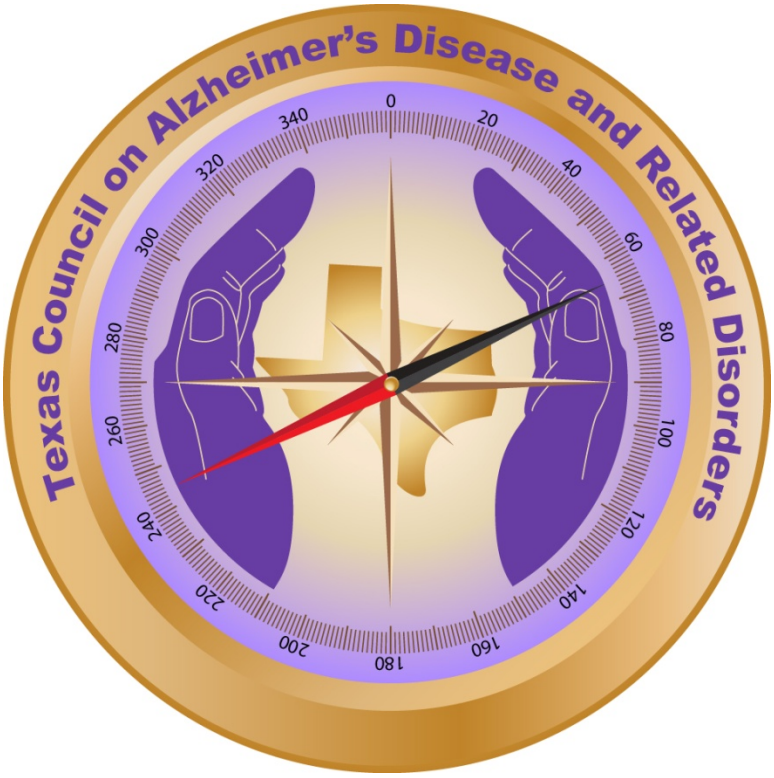
- Garrison Institute on Aging; DNA Bank; and patient care/clinical services for Alzheimer's disease and Parkinson's disease.

UNIVERSITY OF NORTH TEXAS HEALTH SCIENCE CENTER **1-817-735-5440**

Scientific research and clinical trials on Alzheimer's disease and aging; patient evaluation and care through clinics, including a specialty Memory Clinic; and geriatric education.

www.hsc.unt.edu/research/default.cfm

- Clinical trials; research; patient education and care.



TEXAS DEPARTMENT OF STATE HEALTH SERVICES
ALZHEIMER'S DISEASE PROGRAM
1-800-242-3399
http://www.dshs.state.tx.us/alzheimers/default.shtm

TEXAS
Department of
State Health Services

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